

Stories of Hope

These patients have shared their stories with us and with our governing Board. Hear first hand about their hopes for a cure, alongside updates from CIRM grantees who are working to make these patients' hope a reality.

The CIRM Stem Cell Four

At our 2016 CIRM December Board meeting, we invited four people to speak about their experience participating in CIRM-funded stem cell clinical trials. Their stories are inspiring and remind us that the ultimate goal of funding stem cell research is to find treatments that can cure patients with unmet medical needs. We hope that the voices of these individuals will inspire others who are suffering from diseases that have no cures.

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Sickle Cell Disease

Adrienne Shapiro pledged she would give her daughter Marissa the best possible life she could have—wearing herself out if necessary. Her baby girl had sickle cell disease, an inherited disorder in which the body's oxygen-carrying red blood cells become crescent shaped, sticky, rigid, and prone to clumping—blocking blood flow.

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Diabetes

The last thing **Maria Torres** expected was to be diagnosed with type 2 diabetes. She exercised, ate well and kept her weight under control. There had to be some mistake. Maria asked her doctor to repeat the tests, but the results were the same. At 43, for reasons no one could fully explain, she had diabetes, and her life was going to change dramatically.

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Alzheimer's Disease

Adele Miller knew what came next. She had lived it twice already: her father's unraveling, due to Alzheimer's disease, and, a few years later, her mother's journey through the same erasure of mind and memory. So when doctors told her, at age 55, that she, too, had the disease, she remembered her parents' difficult last years.

"She was ashamed," her daughter, actress and writer **Lauren Miller**, recalls. "She was so embarrassed because there's such a stigma." And she worried about her family. How would they handle all this? "I asked her once if she was scared," Lauren says. "She said she wasn't afraid for herself. But she was afraid for me, and my dad, and my brother. She knew what she'd gone through with her parents."

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Stroke

Six months after surviving a stroke, **Sonia Olea** wanted to die. Her right leg was weak, her right arm useless. She had trouble speaking and even small tasks were challenging. Just making a phone call was virtually impossible. One morning, she woke up with her arm pinned in an awkward, painful position. After finally repositioning it, she wanted to call her fiancé, but knew she couldn't get the words out. That's when it hit her. "I thought, I'm only 32," says Sonia. "How could this be happening to me?"

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Spinal Cord Injury

Katie Sharify had six days to decide: would she let her broken body become experimental territory for a revolutionary new approach—even if it was unlikely to do her any good? The question was barely fathomable. She had only just regained consciousness. A week earlier, she had been in a car crash that damaged her spine, leaving her with no sensation from the chest down. In the confusion and emotion of those first few days, the family thought that the treatment would fix Katie's mangled spinal cord. But that was never the goal. The objective, in fact, was simply to test the safety of the treatment. The misunderstanding – a cure, and then no cure -- plunged the 23-year-old from hope to despair. And yet she couldn't let the idea of this experimental approach go.

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Leukemia

Stem cells create life. But if things go wrong, they can also threaten it. **Theresa Blanda** found that out the hard way. Fortunately for her, CIRM-funded research helped her fight this threat, and get her life back. In the first few days of human development embryonic stem cells are a blank slate; they don't yet have a special, defined role, but have potential. The potential to turn into the cells that make up our kidneys, heart, brain, every other organ and every tissue in our body. Because of this flexibility, stem cells have shown great promise as a way to regenerate dead, diseased or injured tissue to treat many life-threatening or chronic conditions.

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Heart Disease

Mary and Tony Goulart didn't need to look at each other. They knew without any hesitation that they would ignore the doctor's advice.

Mary was four months pregnant and a pediatric cardiologist was confirming the worst. The left side of her infant's heart was undeveloped — and that was only the first of several devastating heart defects. The child's life was as uncertain as the next breeze. "Termination is a really good option in this situation," the cardiologist said. "He's unlikely to survive."

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Liver Disease

If the trace of chocolate on **Vanessa Lupian**'s lips didn't give the 6-year-old away, the candy wrappers on the bathroom floor would have.

"That's where my panic came in," her mother, Veronica Lupian said. The wrong food — almost any food — could land Vanessa in the hospital fighting for her life. Vanessa had a metabolic disease that narrowed the list of foods she was allowed to eat so drastically that dinnertime left her staring enviously at the food on her family's plates.

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Multiple Sclerosis

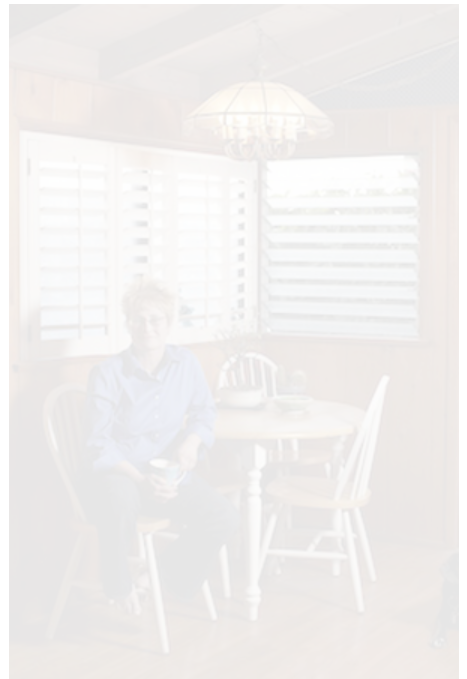
Nan Luke was hitting her stride. Just shy of her 30th birthday, her law career was blooming, and she was in love.

Then one day the left side of her body went numb from the sole of her foot to the middle of her chin, leaving her with the constant tingle of a sleeping limb.

She had multiple sclerosis, her doctor said. Nothing could be done.

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Bone Repair

It was just a little stumble. Or that's what it seemed to **Diana Souza** when she fell while doing chores on her Northern California ranch. But her left arm was fragile and it snapped where an earlier break had healed crookedly. What came next was worse: three surgeries that didn't work, an orthopedic surgeon proposing a fourth, and an arm bone riddled with holes.

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Autism

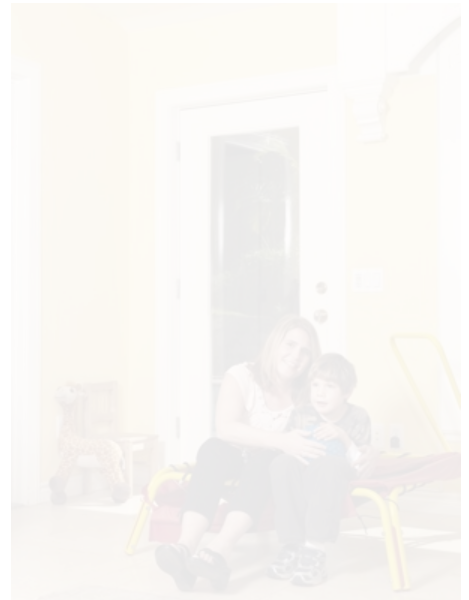
Brandon's dad noticed it first. "He won't look at me," Jonathan Knepher told his wife, Laureen Forman, as they admired their 18-month-old son. "Why won't he look at me?"

Forman hadn't noticed it herself. Brandon looked at her. "What do you mean?" she asked, and then watched as her husband tried to draw their son's attention. "Oh my gosh!" Brandon would not look.

It was the first suggestion that their son had autism.

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Heart Failure

It was grandpa to the rescue when **Fred Lesikar**'s granddaughter tried to put on a pair of jeans several sizes too small. The toddler was stuck. She could not pull them up, and she could not pull them off. Lesikar, then 59, stood on the cuffs of the jeans and began to lift her out of the pants.

But it hurt. Pain radiated across his back and around his chest. It ran through his biceps and up under his chin.

He should have called 911. He will tell you that now. Instead, he asked his stepdaughter to drive him to the hospital.

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Neuromyelitis Optica (NMO or Devic's disease)

In 2008, **Victoria Jackson**, the creator of Victoria Jackson Cosmetics, was all about lip-gloss. Then, her middle child, Ali Guthy, started to lose her vision.

The diagnosis doctors provided was puzzling. The prognosis was worse. Her daughter had neuromyelitis optica (NMO) and she could be blind and paralyzed within four years.

From that moment, Jackson's life would never be the same. And neither would the lives of several researchers.

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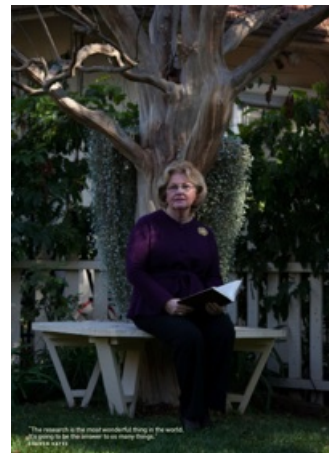
Macular Degeneration

The images on the playing cards wouldn't come into focus, but **Sharon Hayes** kept trying to play bridge, making bidding mistakes as the game went along.

Finally, another bridge player had enough. "She said, 'Sharon, you've got to go to the doctor right now.' And we literally put down the cards and we went," Hayes said.

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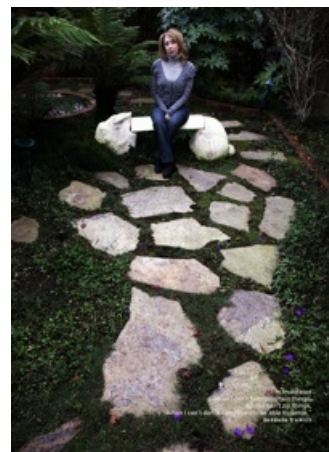
Arthritis

Six days a week, **Barbara D'Amico** hits the gym. "I do intensive workouts. I do weights. I do aerobics. That's my part-time job, to stay healthy," D'Amico said.

She's fighting rheumatoid arthritis. The Redwood City accountant has had the degenerative disease more than 40 years. She can make it seem like a snap; it's anything but.

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ALS (Lou Gehrig's Disease)

Dan Desmond caught himself using a hoe as a crutch as he walked his 6-acre property east of San Diego. It was one of the little hints he ignored until the day four years ago when he couldn't finish a hike. "My legs just weren't working," he said.

He had amyotrophic lateral sclerosis, the doctors told him, Lou Gehrig's disease. He went online to learn more and spent two hours at the ALS Association office in San Diego. "I did not like what I was hearing," he said. "I did not like the way things were going." But he found a way to cope.

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Huntington's Disease

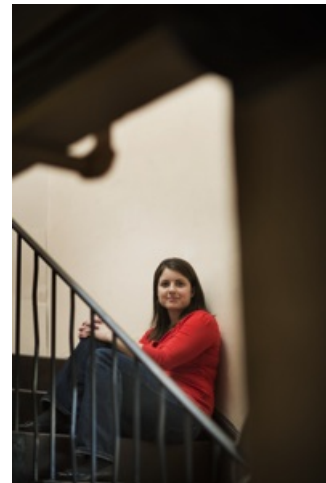
Sherry lives balanced on the odds of a coin toss.

Since she was 9, when her father was diagnosed with Huntington's disease, she's known that she has a 50-50 chance of receiving the same diagnosis. During the next 11 years, as she watched her father fail tragically, his personality changing, his body growing weaker, she coped by staying busy, swimming and playing water polo.

Just knowing she might develop Huntington's is a malady. So many things worry her. "If I trip or fall or mess up at work, I think, 'Oh, I might have HD.' If I'm moody or something, I wonder, 'Is this like the first sign?'"

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HIV/AIDS

It was perhaps the biggest moment of **Loring Leeds'** life, but as he lay waiting for doctors to return his stem cells to his body, Leeds realized it was a signature moment for the crowd in the room as well.

It was 1998, and surrounding him were the doctors and scientists who had developed a treatment for non-Hodgkin lymphoma in AIDS patients—something most of the medical community at the time considered pointless and hopeless. But Leeds' stem cell treatment was even more dramatic, because some of his cells were genetically modified to express an enzyme researchers hoped would short-circuit AIDS.

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Epidermolysis Bullosa

Chuck and Christine Anderson were butterfly children.

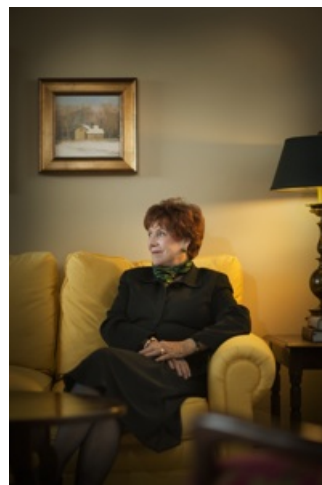
Born with an inherited condition that made their skin as fragile as a butterfly wing, Chuck died at 27 of skin cancer. His sister, Christine, died of heart failure at 14.

"These children taught me an incredible lesson in resilience, determination and good

cheer," says their mother, **Lynn Anderson**. She is the president and founder of the Epidermolysis Bullosa Research Foundation.

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Parkinson's Disease

For **Bruce Wisnicki** and other Parkinson's patients, the benefit of most Parkinson's medications might be summed up with the bromide: "This too shall pass."

Because of the degenerative nature of the disease that depletes the dopamine producing brain cells, medications to control symptoms eventually lose their punch.

"I'm one of the lucky ones," Wisnicki says.

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Deafness

Diane Kaljian's father was paralyzed and bedridden from a stroke. But he could still speak.

"I was hoping to talk to him, but I could never do that," Kaljian said. Her hearing loss was so profound, his low, gravelly voice couldn't penetrate. "I was not able to hear his last words to me," said the mother of three.

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